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YOUNG PEOPLE with Spina Bifida and/or Hydrocephalus —

LEARNING AND DEVELOPMENT

by Leonie Holgate, MCSP SRP

asbah

Association for Spina Bifida and Hydrocephalus

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© Association for Spina Bifida
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22 Upper Woburn Place
London WC1H OEP
Telephone: 01 388 1382

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email : clic@sochara.org / cphe@sochara.org
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ERRATUM

Chapter 3, Page 33

SQUINTS should read:

17 Constant squints, either convergent or divergent; therefore, no BINOCULAR vision

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Association for Spina Bifida and Hydrocephalus

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INTRODUCTION

YOUNG PEOPLE WITH SPINA BIFIDA AND/OR HYDROCEPHALUS

(Learning and development - post 16)

In many post-school establishments for the physically handicapped, nowadays, the proportion of disabilities is one third cerebral palsy, one third spina bifida and/or hydrocephalus and one third other disabilities. Most of the conditions are well known to the professional staff, apart from the occasional rare syndrome, and thus their needs can be catered for from previous experience. The spina bifida/hydrocephalic teenagers, however, are a relatively new group and appear, at first sight, to have similar problems to those seen in paraplegic patients or cerebral palsy. This is true to a point but spina bifida is a congenital condition where the malformation occurs in the early embryonic period resulting in deformities of the vertebrae, urinary tract, ventricular system of the brain etc.; abnormalities not seen in traumatic paraplegia or cerebral palsy. ASBAH publications refer to this in more detail. (See list on page 54)

Many of the young people with spina bifida will be in wheelchairs or walk with difficulty using sticks or other forms of support. Their upper limbs appear to be strong and unaffected. They are, generally, sociable people and very ready to chat, giving an initial favourable impression. Over the past few years this teenage group has been studied by an increasing number of people (references at the end of the book), and their findings have indicated that there are hidden defects which mar the performance and aspirations of these young people. These defects may be apart from, or indirectly

attributable to, the physical difficulties and can be psychological, sexual, sociological or connected with cognitive functioning including visual/perceptual and spatial deficits. The discussion of the psychological problems does not come within the scope of this book and the sexual possibilities are excellently presented in the Young ASBAH series "Sex for Young People with Spina Bifida or Cerebral Palsy".

Most of the purely physical problems may be alleviated by modern medicine and/or surgery combined with the appropriate training. In addition to the easily recognised physical handicaps there are the "hidden defects" of learning: spatial and visual/perceptual awareness, sequencing difficulties, a poor concept of time and memory. This will affect the performance of any manipulative task and their style of performance, resulting in inability to complete routines successfully and to reason logically. Thus it can be seen that nearly all aspects of their daily living and training programme will be affected.

It is obvious that all these problems present tremendous difficulties for the young people and their parents. On leaving school, the majority of these teenagers will not be suitable, at least in the immediate future, for open employment. There are also many who will not be ready for sheltered employment, and many whose future placement will be in a work or day centre. Wherever the young person is eventually placed, it is important that they have received sufficient training to gain enjoyment, reward and success from the situation. They should feel that they have some control over their lives and are able to manage and understand everyday necessities. In order to be in a position to prepare a young person for this, it is necessary to be aware of their difficulties and to have some guidance in the way in which to train and handle them.

The group under discussion here, are those who will not find paid employment because they manifest the sort of problems which make them unsuitable for the competitive

world of employment, even the sheltered type. It is possible for this group to lead an interesting and fulfilled life and to progress in their abilities. This should be a positive goal to aim for, no matter how daunting it may seem at times.

The following quotations from a recent study by RADAR emphasise the need to be realistic about the future:

"Careers officers saw an increasing need for more attention to be paid to the less able of the disabled young people. In view of the increasing non-working population, they thought that further education and training facilities were essential even if only to improve the quality of the disabled school leavers lives without work."

"If these young people, being unaware of the real likelihood of a life of unemployment, suddenly find themselves sitting at home with nothing to do - possibly cut off from their able-bodied peers or even totally socially isolated, with little or no purpose in life and little money on which to live - it is not hard to imagine the despair which could result."

"Should the emphasis instead be shifted to give equal weight to ways in which life can be given meaning and significance other than through employment? Is it not time that all young people, both disabled and able-bodied (for the prospect of a life without paid employment by no means faces only disabled youngsters) were educated to realise that employment is not the only way to achieve self-value? The answers to such questions are by no means easy."

"The prospect of a life without paid employment must be recognised by all educational establishments and they must begin to come to terms with the need to educate young people at school to handle enforced leisure in a way that will enable them to achieve the same sense of self-value and social worth that would otherwise be obtained through employment."

Beyond the School Gate - a study of disabled young people aged 13-19 by Joan Bookis, available from RADAR, 25 Mortimer Street London W1N 8AB

10 The motor. sc ~~threw~~
Andrew

4th August Page 11. 17

- 1 The name of the MUSEUM is called ASHMOLEAN MUSEUM and it is situated in Beaumore Street JUST OFF ST. GILES.
- 2 It take **TEN** minute to walk of the railway station to the museum.
- 3 The museum is open six hours on a Thursday.
- 4 The book STALL attendant or the Duty Friend on the ground floor will advise when it is likely to re-open.
- 5 You would find the booksell on ground floor adjacent to the main entrance.
- 6 Before the school parties are allowed to come in they have to go to ~~in touch~~ contact the museum SECRETARY.

Unrealistic Attitudes: "Immature handwriting of a 17 year old student with spina bifida and hydrocephalus"

PROBLEM AREAS

First of all it is necessary to consider and discuss the problem areas and then to look at positive ways in which specialised help or aids can be offered. Many of the areas will be seen to overlap and it is not easy to divide one deficit from another. However, divisions have been made, in order to facilitate the identification of areas of difficulty.

Unrealistic Attitudes

When questioned, many young people with spina bifida/hydrocephalus have a rather unrealistic outlook for their future. Some have no outlook at all because they have never looked forward and planned ahead; or, it could be that they were afraid to do this. The unrealistic attitude of some of these young people does not appear to stem from the fact that they see themselves as being flawless. They can be disarmingly honest about their laziness, poor ability at writing or maths, clumsiness, carelessness etc. However, they do not appreciate how these defects will affect them in running a home, doing a job, driving a car and so on. This somewhat illogical approach to their future is, as in most other instances, due to several factors which may be broadly looked at as internal and external.

Internal

- It has already been mentioned that there are sequencing difficulties which can affect logical reasoning. This is one of the reasons why they do not understand, for example, that if they are clumsy in the handling of their

wheelchair and knock paint off doorways and run over toes, they could be equally clumsy in the handling of a car. In the same way they do not see why a self-confessed poor memory should interfere with their ambition to be a telephonist. They cannot visualise how their short-comings will hamper them. They recognise a problem but they do not relate it to their ability to perform a task. Their ability and their ambition are two separate items and they find it hard to match them.

External

- In most cases their experience will have been very limited and they will have had little or no opportunity to have experience in things such as managing a home (cooking, shopping, washing, ironing etc), or of sitting in the front seat of a car or riding a bicycle to gain traffic sense. Possibly, at school, the other pupils were in similar situations and so offered no criterion on which to base their own achievements.

Parents are often puzzled by their son or daughter's low achievement at school but feel that if they really tried they could do much better and so they set goals which are beyond the child's grasp. The parents may see the wheelchair as being the only limiting factor and so any desk job would seem to be a reasonable ambition. As parents and professionals become more versed in the subtleties of spatial and visual/perceptual deficits, a more realistic approach should develop. This can be gradually transmitted to the child so that he or she grows up understanding their own problems in greater depth. At the same time because more is known about these "hidden defects", year by year, the training should improve to compensate and, thus, a better outcome can be envisaged.

Judgements of ability, whether it be self or of others, can only be made from experience and it must be remembered that most disabled young people have very limited experience and have been very dependent on

others. Their judgements often reflect the opinions of those around them and this is to be expected.

To overcome these unrealistic attitudes, careful and sympathetic explanations for the parents and for the young person are necessary to assist them to arrive at a fuller appreciation of the problems. The earlier these discussions start, the better.

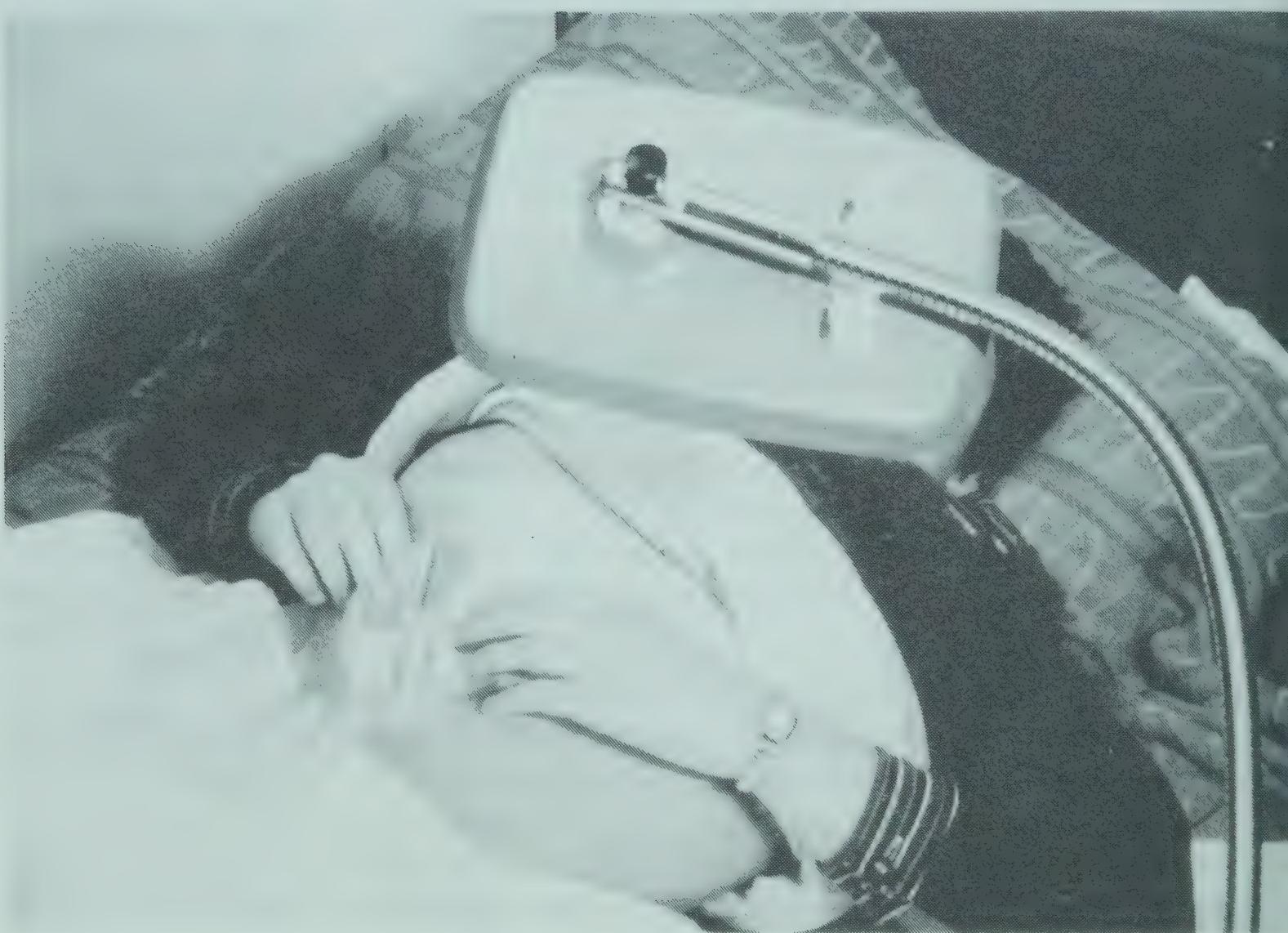
As Dr. Thomas M Gregg, Medical Director of the Dublin National Rehabilitation Board, put it in his address to the first conference of the International Association of Hydrocephalus and Spina Bifida, in Dublin, 1981:

"Some are totally unrealistic and find it hard to accept that areas of work may be unsuitable. Many are not able to judge their own capabilities. Some feel that their parents have high expectations and may be depressed by the feeling that they are letting them down. They have enough problems to cope with, without adding feelings of failure if they have to settle, perhaps, for a sheltered workshop instead of a more illustrious career. In particular, children with spina bifida and hydrocephalus need guidance from an early age.

Spatial and Visual Perceptual Deficits

These will affect the performance of any practical task because the hands and/or the body are required to move in space. Appreciation of a scene or situation set before the student will pose difficulties because they cannot accurately relate one item to another or select the most relevant objects.

Difficulties in gross movement often become painfully obvious, especially in wheelchair manoeuvring when backs of ankles are rammed with foot plates or toes are run over. There are usually tell-tale marks around doorways where paint has been removed. Those who walk may have difficulty in judging their distance from the edge of the kerb and stop short. Stairs and kerbs can be a



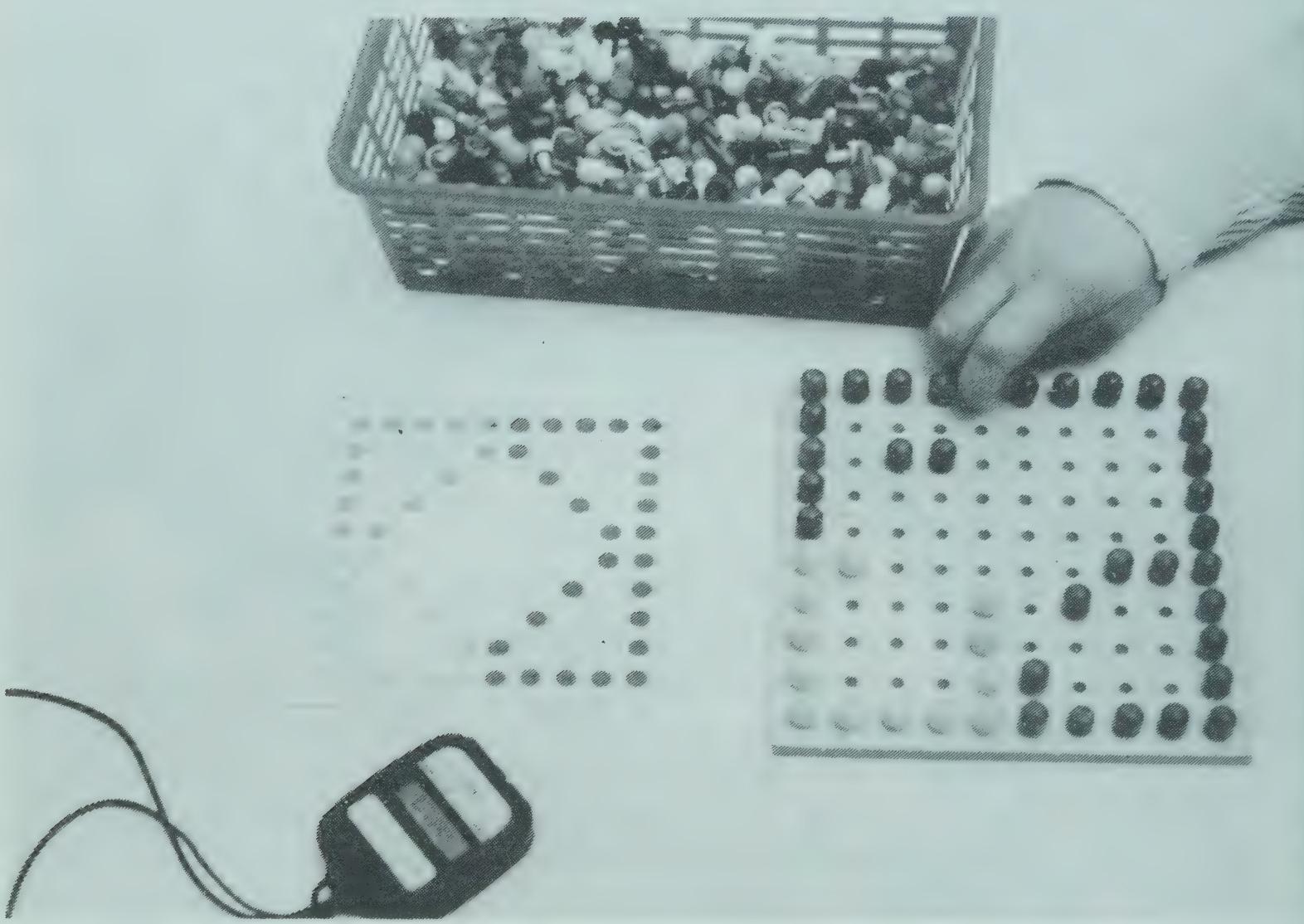
Spatial and Visual Perception: "Attaching a urinary appliance using a 'Stayput' mirror"

terrifying experience as they find it hard to judge the depth of the step and to them it may seem like a bottomless pit.

When finer hand movements are observed, they are seen to affect simple dressing requirements, such as doing up buttons or shoe laces, also any delicate manipulative task using small tools will suffer. Handwriting is often very untidy and, unless there are lines to follow, can wander up and down the page. The correct use of scissors may present difficulties because this requires moving in two planes at once, not only chopping up and down but also squeezing from side to side. Tasks requiring movements in two planes at once can often be a stumbling block and have to be carefully demonstrated or attempts made to reduce the movement to one plane only. Scissors are available, for example, which only need the up and down movement.

Movements requiring rotation are hard for the student to understand and perform well. For example, the application of a urinary appliance: firstly it has to be prepared ready for applying to the body and then it has to be rotated around and positioned. The ability to extract information from a complex scene is often faulty and this is why diagrams, unless they are very simple, are not easily followed or understood. This problem can seriously affect driving potential because they may not see or recognise danger signals in a complicated traffic situation.

It can be seen that these deficits will have wide implications in the training programme for self-care and craft or workshop training. This is an area which has not been well understood by staff and parents and has caused much frustration.



Immaturity: "Difficulty in following a diagonal pattern"

Immaturity

This may be divided broadly into two areas - neurological immaturity and functional immaturity or lack of experience. If a student is watched very critically while they are performing a task, immaturity of movement can often be clearly seen. They handle the tools, be it soap, flannel, ruler, hammer etc., as a much younger child might; even like a toddler.

Examples of this are as follows:-

1. They may attempt to squeeze the sponge using one hand only, failing to bring the two hands together in the midline in order to squeeze and rotate the two hands in opposite directions. This set of movements is too complicated for them to co-ordinate and so they perform the task as a three or four year old in one simple action which is not very effective.
2. Quite frequently the student will persevere with washing one side of the body or one limb and, unless reminded fail to progress to the other side, or limbs. This perseverance is also seen when they are following a line of movement. In this case they may find it difficult to stop and change direction. This can be seen in fine hand operations, such as writing, and in grosser movements when they may not stop their wheelchair in time and bump into a desk or wall.
3. Appreciation of the diagonal is often not well developed. This is seen when the student is asked to repeat pegboard patterns. They can reproduce the horizontal and vertical patterns but become confused when faced with the diagonal lines.



Sequencing: "Spatial and sequencing difficulties in tying a bow"

4. Movements which require crossing the midline of the body may cause confusion. The student will stop at the central point and appear unable to continue unless they are guided across and an explanation is given to them. These simple manoeuvres may need to be specifically taught and practised.

Lack of experience and, perhaps not being allowed to do things for themselves will mean that some of the student's initial attempts at performing a task may appear immature. This would apply to anyone attempting something for the first time and in this case, hopefully, practise makes perfect.

Sequencing

The student may have difficulty in performing the various items of a task in the correct order and so be unable to complete it satisfactorily or, in some cases, at all. They may find the organisation of materials a great problem and thus be incapable of making a start on a piece of work.

At a rather basic level, the sequencing difficulty can be seen when the student omits to put the plug in the bath before turning on the taps or gets into the bath and finds that they have left their towel in the bedroom. These sort of mishaps can happen to anyone but they seem to happen more frequently and more persistently to people with spina bifida and hydrocephalus.

Their difficulty with organisation can also affect their thought processes resulting in poor logical ability. They have various facts programmed into their brain but they do not have the ability to arrange these in sequence to help them come to a logical conclusion. Some may avoid the need to reason through a problem by opting out and allowing others to make the decisions for them. This factor could link up with their poor motivation. Motivation and management depend to some extent on good organisation.

Defective sequencing will affect both the student's abstract and concrete ability. The following extract from Evans: "Rehabilitation with Severe Head Injury" summarises precisely the problems of sequencing deficiency:

- "a. an inability to conceptualise the sequence required
- b. an inability to initiate the correct sequence
- c. an inability to perform the sequence in the correct order
- d. an inability to change from one sequence to another
- e. an inability to interrupt the sequence at will
- f. an inability to alter the speed of the sequence

Although these remarks pertain to movement, these problems may arise simultaneously in other areas, such as speech and thought."

Poor Short Term Memory

Many of these young people suffer from poor memories. Thus there are inherent problems in their ability to remember their training programme. In order to teach a new skill whether it is connected with personal hygiene or in the workshop, the instructions must be simple and short. The student needs to be taken through the task, one step at a time.

It appears that most of these young people have superior auditory retention to visual retention - probably because they perceive what they hear more accurately than they perceive what they see. Simple verbal instructions are likely to make more impression than written instructions or diagrams. These can be used but should be backed up with verbal interpretation.

Repetition is a keynote in the learning process in order to programme the new information into their memory. A certain amount of boredom for teacher and pupil is acceptable in their programme.

Inability to Transfer Knowledge or Skills

If a student has learnt a set routine in one situation, it is quite likely that in another environment this routine will have to be re-taught. For instance, having learnt a bathing and dressing routine at home or at school, the student will not necessarily be able to do this at College where everything is in a different position. In the same way, having learnt to add and subtract in the classroom, they may find difficulty in translating this to handling money in a shop. This fall-off in ability must be taken into account whenever there are changes in the life-style or environment of the young person. They will need time for re-training and also to become orientated in their new surroundings. Reports are sent with the student from one establishment to another and they often seem rather optimistic, but, if the student is given time to settle, then the reports may bear a closer relationship to the student's actual performance.

Speed, Concentration and Motivation

The following criticisms are often levelled at young people with spina bifida/hydrocephalus - "they are so slow", "their concentration is abysmal", "they are easily distracted", "they lack self-motivation". A regular evaluation of these areas during the course of training offers a useful profile of the student's attitude to work and the extent to which they are increasing their involvement. Although measurements would be rather subjective, some sort of scoring system would enable progress to be gauged.

Speed

- The difficulties that some students experience with eye-hand co-ordination slow down their performance. Someone with visual/spatial problems will take longer to perform a task because they make errors and have to correct them. A great deal of their work is done by trial and error. They may have difficulty in understanding what is required of them. With few exceptions this leads them to be slow workers. Occasionally a student will be quick and careless. They are probably suffering from the same basic problems that the others have but approach the task with the attitude of "lets get it over and done with". Tasks involving fine finger dexterity and co-ordination will suffer more than those involving large movements. Examples of areas in which they appear to be reasonably quick are dressing, bathing and moving their wheelchair around. (These tasks are not necessarily performed well.)

Repetition of simple tasks within their capabilities will help to improve dexterity and thus become quicker. Having to accelerate their work rate may be a new experience and it may be helpful to explain this need. At home parents may have taken over because the child was slow and the school bus was approaching or brothers and sisters becoming impatient. Teachers may not have wished to pressurise these children who were something of an unknown quantity and allowed them to take their time or found alternatives for them. Given the opportunity to practise and time to mature progress will be made in this area.

To work within time limits and be aware of the pace at which they work could be a useful exercise to include in their programme. Doing two things at once is a real problem for many and so the two elements of time and accuracy would need to be carefully explained. The task would need to be very simple and the time span short, at least at first, until they had grasped the concept.

Concentration

- The concentration span of the young person with spina bifida/hydrocephalus is short and they are easily distracted. A noisy room with people moving around makes it hard for these young people to keep their attention on the job in hand. If the environment is right it will help to increase their concentration span, for example, a quiet room with workbays.

The scope of the task should be within their capabilities, otherwise they will "switch off" and their attention will wander. Allowance must be made for the fact that they really cannot sustain lengthy periods of concentration on one task. A period of one half hour working on one item is realistic for most of them and then a change of direction should be considered. As the student becomes more skilful and they become aware of this improvement, their concentration span will improve. However, it is important to allow for the fact that their performance can vary from day to day. The reason for this is not always obvious but it may be caused by a variety of factors, or the interaction of these factors eg. transitory raised inter-cranial pressure, a low grade urinary infection or girl/boy-friend trouble, worries at home or no apparent reason at all.

This fluctuation in performance has to be allowed for and the programme drawn up for the student should have a certain in-built flexibility in order to accommodate the student's "peakiness".

Motivation

- It is not surprising that many of these young people appear to have poor self-motivation. All their innate problems prevent them from achieving anything successfully and they find it hard to know where to start. The result of this is, so often, that they do nothing. Added to this is their natural passive nature and the fact that in the past kind people have made the

decisions for them and they have never been expected to initiate or organise an activity for themselves; for example, a social outing or work in the classroom.

In situations where they receive help on a one to one basis, their motivation (and concentration) apparently improves. It is important to find the right balance; if too much is expected of them, or too little, they may adopt a negative attitude and do nothing. Where the interest and attention are at the correct level, they can show a surprising degree of motivation.

If questioned many will profess interest in hobbies and clubs but, in fact, appear to do very little and prefer to sit in front of the television. Although this seems to be lack of motivation, it may reflect their need for outside stimuli. They really require someone to come along and take them to their club or to work with them on their hobby; not necessarily every time but certainly to be aware of flagging self-motivation - someone discreetly in the background to prod or assist as and when required. Ideally this person should not be one of the parents but an interested third party. An able-bodied peer could be the right person and both parties would benefit from the experience.

SUMMARY

From this discussion of the problem areas, it is clear that there are likely to be many difficulties influencing the student's ability to learn and acquire practical skills in any training situation. Some of the students will demonstrate all the problems mentioned, others will have two or three and the fortunate few will appear to have none of them.

Finding work at which the student can succeed, even if it means, to begin with, aiming at a low level, is probably a good start. This will give them a feeling of success and confidence. Due praise at their success is another factor in stimulating them to "speed up", "stick at it"

and "have a go". The saying that "nothing succeeds like success" is very true for these students. A great deal of patience is required to continue encouraging and trying to understand what is proving a stumbling block for them. Many times progress will appear to have been made and then there will be regression. It is necessary to take a long term view and not be daunted by the day to day fluctuations in their capabilities.

R. H. Willoughby and R. G. Hoffman carried out a pilot study on 17 myelomeningocele children with accompanying hydrocephalus and they recommended that "before any placement is determined for the child with myelomeningocele, that child should receive an inter-disciplinary evaluation to not only determine his/her level of cognitive functioning but to specifically explore areas of perceptual or attentional deficiencies." This is a most important point because until the student's specific areas of difficulty are recognised it is impossible to plan an effective training programme.

"Rehabilitation with Severe Head Injury" by C. Evans,
Churchill Livingstone

Willoughby, R H, and Hoffman, R G (Oct. 1979) "Cognitive and perceptual impairments in children with spina bifida - a look at the evidence." Spina Bifida Therapy, 2, No.2

Gregg T, 1981 "Vocational Assessment, Training and Placement"

AIDS TO LEARNING AND ACQUIRING PRACTICAL SKILLS

In order to formulate an appropriate, realistic programme for one of these young people, it is essential to have an in-depth knowledge of the condition and also recent, detailed psychological and physical assessment to hand. A multi-disciplinary approach is desirable with plenty of opportunity for exchange of ideas and findings.

From experience and discussion with staff dealing with spina bifida and hydrocephalus over several years it appears that the following aids and techniques have proved to be helpful.

Consideration of Intellectual Level

When starting with a new student in a post-school training situation, goals have to be set and a framework constructed within which it is possible to work. It will be very helpful if a recent intelligence quotient assessment is available. To consult one seems an obvious first step but it should be taken further and the various sub-tests also looked at, as these give the clues to where the strengths and weaknesses lie. Where possible access to a full psychological report or to the psychologist could be instituted to everyone's advantage.

It is vital to pitch the programme at the correct level as an over ambitious programme will almost certainly mean failure and this may be the last chance that a young person has to train for the future. They have often experienced repeated failures throughout their younger

lives and, therefore, realistic goals must be set in order to achieve success.

Colour

Watching the students perform the tests on visual perception and spatial awareness, and seeing the results of the colour-coding in the workshop, it is clear that colour appreciation is good. This is also born out by the orthoptist's report. There appears to be no more problem with colour recognition than in the normal population. Colour could, therefore, be used as an aid, eg., when giving right/left instructions (with which they often have difficulties) or when teaching the correct way to hold a tool. Lists of instructions could be divided into sections by colour so that the student can quickly see which section he/she is working on. Colour coding could be a good initiation task as they are likely to be successful and this will give them encouragement when they are probably feeling apprehensive in a test situation. There are many ways in which their good colour recognition could be used as a clue. For example, in a building with which they are unfamiliar, use colour as a directional aid - the blue corridor, the pink wall, the green door.

Adequate Stability

In order to perform a neat, dexterous movement of the hands and fingers, adequate support must be given to the larger proximal joints, ie. elbow and shoulder. If this is provided, the hands are able to perform to their best advantage. This proximal stabilisation is sometimes lacking and is one of the reasons for poor manipulative ability. In these cases it will be necessary to ensure that the upper arm, and possibly the forearm is well supported when attempting delicate movements with the hands and fingers. Carrying this one step further, if the trunk is supported, the arms as a whole are able to function more effectively. This support can be supplied

by having the table or workbench at the correct height, a wide body strap or extra padding on the wheelchair. When applying urinary appliances, pillows under the arms to give good support and allow better function of the hands are helpful. Conversely it may be necessary to stabilise the object on which the student is working. For example, when weaving a stool seat a clamp to hold the stool steady will leave both hands free to work more effectively. In the workshop, a fixed saw can assist the performance of a task. Good support of arms and object on which they are working, together with stable seating, will certainly improve hand function.

Simple Instructions

When teaching a new skill, sentences should be kept short; simple everyday words used and the student taken through the task one step at a time. Any visual instructions will need to be clear, simple and free of too much detail. It is advisable to go over the diagrams or written instructions with the student to ensure that they have fully understood. Slow progress and constant repetition has to be anticipated and accepted.

Backward Chaining

The Principle of backward chaining is to allow the student to end on a note of success. When learning a particular strategy, e.g. making a cup of tea, they are guided and assisted through the various stages and allowed to complete the operation, in this case to pour out the tea. In this way they can feel the pleasure of finishing the job well. The next time they will be allowed to do the final two stages of the operation, i.e. put the milk and sugar in the cup and pour out the tea. The task is taught backwards but the student is always successful and this is a great encouragement; rather than fail in the first two or three stages and then have the feeling that here is something else with which they are going to have trouble. This method can be quite

effective in teaching practical tasks, which appear to be presenting difficulties.

Recall

Knowing that these young people have memory problems it is good practice to allow time at the end of a training session to go over what has been done, item by item. In this way trying to develop their memory by linking one item with another while at the same time attempting to imprint a pictorial image of what they have done, on their memory. It is well worth allowing for this reinforcement time, in the programme. Ideally it should be arranged on a one to one basis, but it can be used as a group exercise, trying to ensure that everyone makes a contribution.

Talk On The Subject

Distractibility is another factor that influences the speed of their performance, so aim to direct any conversation to the task in hand. Eg., when teaching personal care (bathing, dressing) it is easy to introduce an extraneous subject such as what they watched on T.V. last night. Then all activity will stop while they tell you about the football match and which team they supported. A useful maxim is "talk about the task in hand" and keep other conversation for later. Some students appear to have a great need to verbalise, so use this talent by encouraging them to talk about what they are doing. In this way they can use their talkativeness to assist in the learning process and it may encourage them to be more observant. This method is used by the police in their driver's training programme and also on the advanced motorist's course.

SAMPLE CHECK LIST

FIRST LIST

PROGRESSION

1. Get out of bed into wheelchair
2. Fold back sheets
3. Put on dressing gown
4. Collect bath towel
5. Collect soap, flannel, sponge
6. Collect deodorant, talcum powder
7. Go to bathroom with 4,5,6

8. Empty bag in toilet
9. Arrange towel and wash things on stool within reach of bath
10. Put plug in bath
11. Run water, testing for correct temperature
12. Get undressed
13. Turn off taps when sufficient water is in bath
14. Remove bag etc.
15. Place in disposal bin

16. Retest temperature of water
17. If temperature is correct, get into bath
18. Wet body and arms
19. Wash with soap
20. Rinse off
21. Wash carefully around stoma
22. Arrange towel on wheelchair
23. Get out of bath
24. Dry thoroughly all over

25. Apply deodorant and talcum powder
26. Put on dressing gown
27. Go to wash basin to wash face
28. Collect all wash things and towel
29. Return to bedroom.

BLUE

GREEN

YELLOW

RED

1. Get out of bed
2. Collect wash things
3. Go to bathroom

4. Run bath
5. Remove urinary appliance

6. Get into bath
7. Wash thoroughly
8. Wash around stoma
9. Get out and dry.

10. Wash face
11. Collect wash things
12. Return to bedroom

Flexi-Time

Concept of time is often poorly developed in these students and they find it hard to work within set limits. They do not respond well, as a rule, to being pressurised. If they are allowed sufficient time they will often concentrate and complete a task although it has taken them considerably longer than anticipated. Research has shown that as the child grows older their concentration improves. However, it is still not good. The student may need more frequent breaks than would normally be allowed in order to relax and recharge their batteries. Praise and encouragement for what they are achieving is a great stimulant and an aid to concentration. It can be seen that the way in which training time is allocated and divided may have to be quite flexible, in some cases giving longer periods because someone is a very slow worker and in others a succession of shorter periods. Ultimately, the goal would be for the student to be in a position to conform to a set programme, but in the early days this may prove to be a hindrance to their progress.

Check Lists

As a means of aiding memory, sequencing and organisational ability, check lists are invaluable. They can be used for a variety of daily activities eg., personal care, shopping lists, organising work material in further education or workshop, arranging social outings making telephone calls etc. The check list needs to be carefully constructed taking each phase step by step and done in conjunction with the staff involved, and the student. It is necessary to foster the student's interest and involvement, so they should be included in all decisions. Before drawing up a check list it is important to observe the student closely. If they are fairly able then only broad outlines need to be given. On the other hand, if they have severe problems with organisation and memory, their list may have to be very

detailed. An excessively long list can be confusing in itself, not to say boring. However, if it is broken into sections of, perhaps, ten items and colours used to differentiate between the sections plus squares for ticking off as each item is completed, it becomes more interesting and rewarding. Even when they are "word perfect" some students cling to their check lists as it is something concrete and reassuring.

Question And Answer

Another approach to training is to ask the student how they intend to tackle a task and why they are doing it, rather than giving them straight instructions. This encourages the student to think for themselves and introduces the realisation that they are able to make decisions for themselves. Where a completely new activity is being taught this approach would not be appropriate but when dealing with a subject with which the student has some experience this method can be very productive. Many of the students, as has been seen by the sequencing difficulties, find it hard to visualise forthcoming events and by forcing them to question what their next move should be, they have to project their thoughts forwards. Naturally, due to their apparent passivity or lack of motivation, there is the tendency to tell them to "do this", "do that", "now do this", etc., but if instead "what are you going to do next?", "what do you need?", "how are you going to get that?" etc., is asked, the student must try to visualise their next step and rationalise it. This approach has been seen to work where an intensive course of personal care and independence training is undertaken. Here quick improvement in performance is sought and there is little opportunity for repetition. Very impressive improvement can be made in one week but it has to be admitted that this improvement may not be maintained for long. However, this method of stimulation certainly has its place alongside the other more pedantic methods of training.

Parental Involvement

Any structured programme for the student should be explained to the parents or guardians. It is necessary to have their co-operation and also to utilise their experience where possible. To actually involve the parents in the formation of the programme may not be practicable but it will probably have much more chance of success if the parents are fully informed. They will then see themselves as part of the team and, also, be able to carry on with the same approach when the student is at home. Continuity and conformity are real essentials in the teaching programme. There is a danger that the student may feel that what he or she does at college or training centre has nothing to do with their behaviour or way of life at home. How this parental involvement is developed depends on the location of the college/workshop etc. to the home and, to a great extent, on the circumstances of the student's family and their willingness to be included. As with any child, able or disabled, the parents interest is of paramount importance. Parental involvement may be fostered by regular meetings, regular reports and two way visits between parents and staff. The parents are in a position to offer very helpful information about their son or daughter's management and staff should be willing and ready to accept this. Many parents genuinely welcome the opportunity to discuss problems, worries, triumphs and it is time well spent and reflects in the student's ability to integrate and benefit from the training establishment. One of the observations made by Joan Bookis in her study of disabled young people between the ages of 13-19 (Beyong the School Gate) was: "All the careers officers emphasised the absolute necessity of involving parents in the decisions made concerning their child's future and recognised that parents could provide invaluable information about their child's personality and potential."

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SUMMARY

First of all, know the student. Use every available source of information eg. professional reports, parents' viewpoint, test results, your own critical observations etc. Then aim to teach through strengths such as superior auditory retention as compared with visual retention, or, in rare cases, vice versa. Utilise good colour recognition. A student's willingness to talk may be turned to advantage. There will be areas of strength and these should be exploited to enhance the teaching programme. Repetition should not be avoided. It may be boring as far as the teacher is concerned but it need not be for the pupil. This is one of the best methods of teaching for this group; frequent and repeated instructions. It could be compared to a young child who likes to hear the same story over and over again until they are able to repeat it word for word. Too much variety will only cause confusion. As the student learns, be prepared to learn from them; attempt to recall at the end of the student's career, what steps had to be taken to gain progress. This is a learning situation for all who deal with this disability. Although they may appear, and indeed be, immature, try to treat them as an adult. They are aspiring to adulthood and if they continue to be treated as a child they will respond childishly. It is important to give them the dignity of being considered as young adults and to allow them to make decisions for themselves. Some of their decisions will not be the wisest but by experiencing the results they will, hopefully, learn to make a better choice next time.

PROBLEMS WITH EYESIGHT

Although this account is primarily concerned with the cognitive and visual perceptual problems encountered in young people with hydrocephalus, it is necessary to draw attention to the eye deficits which may be present.

A detailed assessment routinely carried out on 39 students at Banstead Place* showed that in only five was no abnormality detected. The following table shows the most common defects found:-

Total=39

Visual Fields

- | | |
|----|--------------------------------------------------------|
| 17 | Field of one eye slightly constricted; other eye full. |
| 5 | Constricted fields. |
| 2 | Difficult to assess; therefore, results unreliable. |
| 15 | Full Fields. |

Squints

- | | |
|----|----------------------------------------------------------------------------|
| 17 | Constant squints, either convergent or divergent; therefore, no vision. |
| 7 | Intermittent squints. |
| 10 | Latent squints. } Full binocular |
| 5 | No abnormality detected. } single vision. |

* Banstead Place Assessment Centre for Young Disabled People, Park Road, Banstead, Surrey.

Glasses

16 Wearing glasses.

Nystagmus (eye wobble)

- 4 Manifest nystagmus.
- 2 Latent nystagmus.
- 19 Nystagmus on versions only.
- 14 No nystagmus.

Binocular Vision

- 17 No binocular vision.
- 7 Intermittent binocular vision.
- 15 Full binocular single vision.

From this table it can be seen that a high percentage of this group had some abnormality of their sight which could affect their performance in practical ways. Most people dealing with this group as children are aware of the squints resulting from the hydrocephalus but sometimes these other less obvious defects may be present. Quite often both they and the parents are unaware of any problem other than possibly having to wear glasses. If some of these abnormalities were fully explained, it could help them to compensate or to understand the effect of the restriction.

Visual Fields

Visual field restriction can vary from "tunnel vision", or worse, to just missing cues on the periphery of their vision. This may explain occasions of so-called carelessness. To overcome the difficulty they have to be instructed to turn the head in order to scan the immediate horizon. They are not always aware of any reduction as some have always had this amount of field vision and to them it appears normal. The narrowing of their visual field may have been progressing slowly and so it has gone unnoticed. If there is limited field of

vision on one side, work or material should be presented on the good side, otherwise it may be missed or ignored.

Nystagmus

A severe nystagmus may make it difficult for the eyes to be held in focus on an object or a task and this could affect the concentration, the performance and the perception. Sometimes the nystagmus can be steadied by turning or tilting the head. This head posture is acceptable if it enables the eyes to remain steady. However, someone not understanding the reason for the head posture, may urge them to hold the head straight and this would not be helpful and, in fact, may hinder performance.

Squints and Binocular Vision

A squint or disturbance in binocular vision may mean that only one eye is being used effectively at a time. Using one eye flattens the image and interferes with the appreciation of perspective. Occasionally there is alternation between the eyes and one eye may be used for distance vision and the other for close work. If the focus is alternating between one eye and the other, the scene may appear to jump about and this can influence the performance of delicate tasks and may also be one of the reasons why apprehension is seen out of doors, crossing roads and managing kerbs. Sometimes an attempt to control the squint and use their eyes together, results in a compensatory head posture being adopted and this they should be allowed to maintain.

SUMMARY

This is a simple explanation of the orthoptist's findings but it indicates how important it is to have a detailed assessment and how worthwhile it can be to discuss the

results with the orthoptist. They can give valuable advice on how to cope with some of the problems.

If any young person is contemplating learning to drive they should have their eyes carefully and expertly assessed both for their own and other's safety.

Students may need to be reminded to wear their glasses, where these have been prescribed, and, almost as important, to clean their glasses. This may seem obvious to most people but where the memory and motivation are poor these very simple things may be overlooked.

I would like to thank Mrs. Margaret Parkinson, DBO, Orthoptist, for her help in writing this chapter.

CASE STUDIES

Introduction

No two people will present in exactly the same way. This is rather an obvious statement but it is very true of the group under consideration. There is a growing danger of making sweeping statements and generalisations about people suffering from spina bifida and/or hydrocephalus. It must be remembered that some go through their schooling and training periods with no more difficulty than an able-bodied youngster so it is necessary to keep an open mind when meeting one of these young people for the first time.

The first impression made by someone with spina bifida/hydrocephalus is usually good but may mask underlying problems, which only come to light on better acquaintance, and of which they themselves are unaware. This indicates why the final achievements at school or college are sometimes disappointing and again emphasises the need for very careful assessment of their practical performance and their learning ability.

The following are four case studies which highlight the differences as well as the similarities of those suffering a degree of brain damage as a result of this condition. It should be mentioned that when adding up the good points and the bad points, the former outweighed the latter, and this is important to remember.

CASE STUDY 1 ... Olive

Olive came from a very caring background. The parents were elderly and beginning to become anxious about Olive's future, although, at this stage, they had not wished or known how to consider the problem realistically. There was one brother, considerably older and Olive had been treated almost as an only child. The parents had, understandably, been over-protective and she had led a very sheltered existence.

Olive had always attended a normal school but had received her education from a Physically Handicapped unit within the school. She claimed to have only one friend but was cheerful despite this apparent isolation. Her school report showed that she was a low achiever with poor concentration and was a very slow worker. At the time of leaving school she was dependent for most of her personal care.

Physically she was severely disabled being totally wheelchair-bound and doubly incontinent. There was severe weakness and curvature of the spine and she always needed one arm to support her trunk. This made it difficult for her to perform two-handed tasks. She had had epilepsy as a child but this was well controlled by drug therapy.

Olive presented as a pleasant, friendly girl, ready to converse with adults. She had a very neat and clean appearance due to her mother's loving care. The parents had always done a great deal to help because they did not like to see her struggle and felt that it was degrading for her. Because of her pleasant appearance and self-effacing manner, it was felt that she may have potential for some form of vocational training despite her severe physical limitations. She certainly had an unrealistic approach to her future and this had, in part, been fostered by her parents who had an underlying fear of Olive being placed with mentally disabled people and this had reinforced their unrealistic attitude.

On testing it was found that Olive had significant intellectual impairment which was not immediately apparent on first acquaintance. She had spatial difficulties and lack of organisation and although her verbal ability fell within normal limits, her restricted vocabulary lead to difficulty in expressing herself. Her executive skills were poor where any manual dexterity was called for and she was inordinately slow. She would, however, engage in simple repetitive tasks without supervision for a period of an hour. On the recreational side, providing that activities (swimming, riding) were organised, she would voluntarily participate but without any obvious enthusiasm or progress.

These observations combined with the physical limitations indicated that Olive could not undertake vocational training or realistically look for complete social and domestic independence. She would always require care and support but, with further training, she may be able to take over some areas of personal care and in this latter aspect she already showed some surprising ability.

The recommendations based on Olive's assessment were:-

1. To help the parents to understand the reasons and implications of their daughter's level of achievement. This was, naturally, disappointing for them but they appeared, initially, to accept the findings and were co-operative.
2. To find a local Day Centre which Olive could attend, looking towards possible residential care if and when the parents could no longer manage the physical stress of caring for their daughter.
3. To consider Olive taking holidays away from her parents as a gentle preparation allowing both sides to adjust to periods of separation.

It was subsequently shown that Olive and her parents could not fully accept these recommendations. She gradually stopped going to the Day Centre as she

considered it beneath her. This outcome indicated that the parents required on-going contact with someone with experience who could support and advise them. There were probably shortcomings in the Day Centre itself and maybe it was not sufficiently flexible in its approach to make the work and conditions attractive. It had been noted in her assessment that when working with others, her tolerance and concentration could be extended and her own personality created a cheerful atmosphere. There appeared to be no facility for further training in personal management, leading to greater independence. If this had been included in the Centre's programme, Olive and her parents could have seen more reason for attendance and persevered.

CASE STUDY 2 ... Neville

Neville came from a closely knit and loving family. The parents were, perhaps, not sufficiently informed about his condition and this produced a rather defensive attitude towards Neville's disability at first. The home had been minimally adapted, ie. a hand rail in the bath, but Neville was ambulant and able to walk fair distances using two sticks. For long distances he required a wheelchair. He had received his education at special schools where he had also been able to enter into some active sports, eg. football, cricket and snooker. He was doubly incontinent. Early hydrocephalus had not progressed and so he had not had any shunt procedure.

Neville presented as a quiet, retiring young man who had little self confidence and avoided eye contact. He was always sure that he would fail at school and this led him to allow opportunities to pass him by and to appear shy and nervous. He found it difficult to communicate with his elders but was on good terms with his peers and well accepted by them. The parents were very interested in Neville's achievements but did not know how to help him and this was probably aggravated by their somewhat unrealistic hopes for the future. Neville was very much influenced by his father's way of thinking and this no doubt increased his avoidance of failure situations as he did not want to disappoint his father.

Assessment revealed that there were large gaps in Neville's general knowledge and understanding but it was also felt that he should not be judged too hastily. Perceptual and sequencing problems were in evidence which seriously affected Neville's performance and the low scores in these areas tended to suggest that he was duller than he really was. Overall he had an erratic profile of intellectual abilities combined with impaired confidence but he also had some sound social skills. On the credit side, although he had not achieved independence in his personal hygiene, he was eager to learn and was interested. In Further Education Neville

showed potential for further achievement in numeracy and literacy. His spatial difficulties hindered him with craft activities but he was capable of simple repetitive jobs and sustained concentration for lengthy periods. Providing he was given initial guidance in positioning he could cope with packing tasks. He was given the opportunity to have a course of lessons on a driving simulator but he appeared totally confused, due partially, no doubt, to his sequencing difficulties, and his reaction times were very variable.

These findings indicated that Neville would require a structured routine and when this was adopted for his personal care programme, he responded enthusiastically and determinedly used his check list and learned in a robotic manner. He achieved his goal of independence, but it was observed that he was unable to adapt to any break in the routine and for this reason he would need discrete supervision to cope with these occasions.

The recommendations based on Neville's assessment were:-

1. Wherever Neville went, to provide a structured programme and a strict routine, using check lists where necessary. Working within this framework, to allow for periods of adjustment in new situations or environments.
2. To aim at placement in a sheltered workshop with hostel accommodation. In time and allowing for further maturing and development, it was felt that Neville might achieve open employment.
3. To buy a Batricar to increase Neville's outdoor mobility and, thus, his social contacts. In this way he could possibly continue with his archery, swimming and riding which he greatly enjoyed and at which he excelled.

At first there was no vacancy for Neville at the sheltered workshop of his choice and he had to return home and attend a local day centre. The father was very

supportive to Neville at this time, as he had been co-operative during the assessment period, and he had adjusted his ideas on Neville's future. Eventually, Neville gained a place at the Sheltered Workshop and coped with the hostel accommodation. He demonstrated his continuing maturity, perhaps most of all, by his increased confidence. The fact that he had an understanding and loving family in the background undoubtedly helped him to go forward in this way.

CASE STUDY 3 Eva

Eva was fairly able physically and walked using elbow crutches, only needing a wheelchair for longer distances, ie. 1/2 mile or more. She had occasional nocturnal incontinence but this may have been associated with Petit Mal. The family consisted of mother, father and four younger children. The parents were caring and supportive and aware that they probably did too much for Eva. They had a family business run from home and rather isolated from the local community. This had meant that, apart from school, Eva had not had much opportunity to mix with her own age group and the opposite sex. Eva had attended a normal school for all her education but had played a rather passive role preferring to be an observer rather than a participant. This was one of the main areas of concern to the parents who felt that she did not make best use of her abilities. Prior to coming for assessment Eva had attended a training college for one month but this had not been successful as she had not, or could not, sustain the level of personal independence required and had not shown sufficient involvement in the training scheme organised for her. Naturally, this had been disappointing for the family but had left Eva, apparently, unmoved. Her manner throughout had been quiet and agreeable but excessively passive.

The initial aims of the assessment were to examine the extent of poor initiative and motivation; to improve her self image and, thereby, enhance her personal awareness and care; depending on the success of the first two, it was hoped to examine her potential for open employment. The staff, like the family, soon became aware of Eva's unreasonable inertia to which there appeared to be no psychiatric overtones. In her personal relationships she was quiet and pliant but was more forth-coming with her peers than with the staff. The latter was a fairly normal attitude for a girl of her age and background. Intellectually, she fell within the low average range and

presented with some perceptual deficits. However, her conceptual understanding and memory were good and her difficulties appeared to be related to her poor motivation. Her lack of assertion had lead to an impression of being dull-witted. Although she enjoyed social contacts and activities such as the cinema or going to the pub she lacked the initiative to plan these for herself and relied on others to do the organising. It was felt that Eva could benefit from more involvement with her own age group and she showed signs of increasing interest in the opposite sex.

Following a period of training she was able to undertake all aspects of personal care, laundry and bed changing and so she was allowed a period of living in the independence flat. She coped well with this and prepared her breakfasts and attended to the associated shopping and money management. She did not readily ask for help and so some discrete supervision appeared to be necessary to assist her in maintaining this level of independence. What was even more significant was that she obviously enjoyed this opportunity to manage on her own. In the workshop she appeared to have the potential for training in the use of hand-tools, progressing to precision tools but again lacked motivation to instigate a project and to develop her manual skills. However, it was noted that she worked better in a group and, that once her interest was aroused, her concentration was good. On the credit side, Eva was punctual and regular in her attendance and was always respectful and attentive. This indicated that she should fit well into a sheltered workshop environment. In Further Education she commenced learning to touch type but it was clear that she would require considerable help with the theory, if she were to consider this as a vocational skill. The Petit Mal and occasional Grand Mal precluded Eva from undertaking a driving assessment.

The recommendations based on Eva's assessment were:-

1. To encourage her to develop more self-reliance and an appropriate relationship with her parents,

commensurate with her age. This would undoubtedly involve guidance and support for the family.

2. To organise more involvement with her own age group and the opposite sex. This indicated that a residential situation with a workshop attached (or in the vicinity), could provide the right environment. Eva had fitted into the residential situation of the assessment centre and reacted well and developed a lively relationship with her peers, although she remained quiet and secretive with the staff.

Unfortunately, the area from which Eva came did not have the required setting for her and so she returned to her family. It was arranged for her to visit a residential workshop outside her district, but by the time this took place Eva had become used to the protection of her family and lost her desire for more independence and so refused a place. Although the parents were understanding they could not resist the temptation to over-protect. Two days a week Eva attended a day centre and one day a week she helped her father in the family business. Later she also spent a day a week in a children's nursery which she very much enjoyed.

The assessment period had shown that when Eva was with her own age group and given the opportunity to make decisions for herself, she became a livelier person. At home she adopted the role of the child waiting for someone else to take the initiative. The ideal situation would have been for Eva to move straight into residential accommodation with sheltered workshop employment and to have continued to mature uninterruptedly. Although she would undoubtedly go on maturing in the home situation this would not develop to the same degree and her passive nature could take over. It was unlikely that she would develop into a completely independent person whilst at home.

CASE STUDY 4 Terence

Terence's home background was not as supportive as those in the previous three case studies. He came from a large family, many of whom had already left home. His parents had separated and this had left the family, financially, at risk. Because of the many pressures on the mother, Terence had been left to his own devices and, superficially at least, appeared quite able and mobile. He had spina bifida but had never been diagnosed as having hydrocephalus and had not suffered any fits. He was doubly incontinent and had an ileal loop with which he coped independently. Terence was already nineteen but had not done anything since leaving school. His literacy and numeracy were poor and this combined with other problems made it difficult to find suitable placement. This was the reason for his referral for assessment.

Despite his skilfulness in some areas, ie. wheelchair manoeuvring, swimming, riding, he showed a lack of motivation and enthusiasm in general. Terence had some walking ability but he had abandoned this and preferred to use his wheelchair on leaving school. He was able to manipulate the chair speedily and adroitly and mount a seven inch kerb. Terence was independent in managing his personal care but chose a poor nutritional diet and was consequently tired and lethargic. He spent six weeks in the independence flat and coped well with this except for the diet. Terence was popular and had many friends both at home and amongst the other students. He related quite well with the staff but tended to be rather diffident. This was off-set by his quiet sense of humour.

On testing it was shown that he had low average intelligence with a verbal score below that of performance and no specific perceptual deficits. He was poorly motivated and required stimulation to achieve his potential. This may have been aggravated by him being allowed to drift at home; and also, possibly years of

poor nutrition influenced his inner drive. In Further Education his performance did not match his intellect and he appeared to be disinterested. This was also apparent in the Workshop where he demonstrated some promise initially but then was satisfied with success at a low level and did not show interest in developing. He seemed not to have the ability to sustain effort even when the results were good.

During the period of assessment Terence achieved certain success; he proved himself a very able horseman and, using his Mobility Allowance, bought himself a Mini automatic and learnt to drive. Following a trial period at a Sheltered Workshop he was offered a place. The areas of concern which remained on his leaving the Assessment Centre were his ability to sustain effort and interest and his responsibility towards money matters.

At first, he coped with the increased responsibility of the Workshop. He had greater independence and mobility with his car. After a while, however, he allowed his social life to encroach on his work and he was also under some pressure from home to return, as his allowances were needed to boost the family income. He had one or two scrapes with the car and it spent considerable periods in the garage.

The outcome seemed to indicate that Terence really required more supervision and guidance than was always available or, at first, seemed necessary. He clearly did not have a sufficiently developed sense of responsibility and was unable to sustain effort in any project he undertook. The family also would have benefitted from counselling on having a positive and long term view of Terence's future. It was very disappointing that a young man showing potential, was not able to fulfill this promise. Something further in the form of training followed by appropriate supervision was required.

SUMMARY OF CASE STUDIES

Each of these young people shared areas of common concern; apparent under-achievement and no clear direction as to their future. In each case this was presented in a slightly different way. It is rather like looking at a jigsaw; many of the pieces appear to be identical but on closer scrutiny each has its own characteristic and will not fit into another's slot. This is the danger in seeing a disability group as 'all the same'. It would be possible to continue describing individuals and highlighting problem areas but from these four it is possible to identify important issues which require attention and action.

Above all other concerns should come those of the parents. It is so important that they have easy access to those dealing with their children at whatever level, from birth onwards: and that information concerning their child's disability and its specific effect on him/her should be readily available. This would help to avoid anxiety and unrealistic hopes and prepare them for a future which will be fulfilling for their son/daughter, although possibly different from what they had originally anticipated. From time to time it may be necessary to offer parental counselling and this should not in any way be considered as an admission of failure but rather as a positive step towards better understanding. In all four cases quoted, if the parents had had better education concerning their child's disability and abilities many of the problems the child was encountering would not have arisen. Deeper understanding will not remove the disability but it will certainly allow the abilities to be developed.

Another important issue is the lack of appropriate centres, workshops, residences which will provide the right environment to enable these youngsters to continue to develop and mature. This particular group shows evidence of this continuing well beyond the school leaving age and although they may not progress far

academically, except at a basic level, they are capable of considerable achievements in social and personal independence and awareness. Day centres and workshops should adopt a more imaginative and flexible approach in what they are offering their clientele and it would be encouraging to see a more even spread throughout the country. This is discussed by RADAR in the paper "Day Centres for Young Disabled People". Perhaps more publicity or emphasis should be given to the Sheltered Placement Scheme and the part that Manpower Services Commission are willing to play in the employment of disabled people. For those who are ready to leave home but are unable to cope with total independence hostel accommodation or residential homes would appear to be the answer. So often this is seen by the young person as an "institution" or like going back to boarding school. Ideally, residences or hostels should be comparatively small and situated in the centre of the town, close to shops, cinema, cafes etc. This would surely be more attractive and could offer a satisfactory permanent base or be seen as a good step towards living alone.

Looking at these four young people it was very obvious how important it was to study or assess them in as much detail as possible in order to understand their difficulties and to give them realistic direction for their future. The sad thing was that so much of this excellent knowledge and advice was wasted because the facilities were not available to carry them out.

"Day Centres for Young Disabled People", Kent, Massie,
Newman & Tucker, RADAR, 25 Mortimer Street,
London W1N 8AB

APPROACHING THESE SPECIAL NEEDS

We have a considerable group of teenagers and young people in their early 20s with spina bifida and/or hydrocephalus that we are seeing for the first time. There are a few isolated cases who have attained adulthood, some in their 50s or over, but they will have been seen by very few staff working in colleges of further education or residential situations. Therefore, it is impossible to draw on past experience when faced with some of the complexities which this condition may present.

It is natural to use a framework or to set goals which we as able-bodied people see as being good or indicative of independence. These goals we should hope to achieve because we are physically able.

The same goals are not always realistic for someone who has cognitive and perceptual problems in addition to severe physical limitations. It would be rather like someone saying "you can run, why aren't you in the Olympics?" or "you can play the piano, why haven't we heard you at the Proms?". Maybe we could all achieve a great deal more if we developed our abilities to the "n"th degree but it is not realistic to pursue every ability with such intensity and a middle of the road course is adopted or one which suits our temperament and inclinations. Very often the impression is that much more is being expected of these youngsters with so many difficulties to overcome, than is being expected of their able-bodied peers. This is not to say that they should not be encouraged to become independent and to develop

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the skills which they have but perhaps to put more emphasis on self-reliance and self confidence.

There are different levels of so-called independence, all of which may be quite acceptable to society and provide an interesting and fulfilling life-style for the individual. To ask for help for certain things is not always a sign of dependence but may demonstrate a mature level of independent thought. Many of the young people with whom we are concerned are going to require on-going discrete supervision. This may mean that they cannot be left to live entirely alone but will need sheltered accommodation with someone standing by to give assistance when it is necessary. They may even need help on a regular basis because some tasks are physically or perceptually too time consuming for them to perform. This could mean that the routine of getting up, dressing, having breakfast and ready for the day could be accomplished in one hour rather than two and leave them relatively fresh to start their day. They should be fully aware of all that is being done so that they are in a position to direct or take over in a case of emergency. The aim is to improve their quality of life and to increase their confidence which is so often lacking.

Over and over again it is seen that this group find it very hard to maintain standards and left alone they may slip back into a totally unacceptable level of hygiene and nutrition. This will be seen as failure and they could lose a placement and perhaps be returned to parents or to residential care which is so often not the most appropriate position for them. They become despondent and the downward spiral begins. If the original placement had contained some care and supervision (possibly on an ad hoc basis) they could have been helped through the bad patches without loss of face. It has been seen that these young people do continue to mature and develop, albeit very, very slowly and they should not be downgraded too hastily otherwise this continuing process may be halted.

It is very important to give credit where credit is due and so often what these young people do manage to achieve is quite amazing when their physical and cognitive difficulties are considered. They are truly performing at their highest potential which is more than many able-bodied people can claim. We should not be surprised when they slip from time to time. A helping hand would be more appropriate than a wagging finger at such times.

There is a great deal to be learnt from the manifestations of this congenital disability and most people who have dealt with it, especially in the adolescent stage have had to revise their ideas and approach. If they have not, they have been heading for trouble. It calls for flexibility, imagination and patience. No-one has the complete answer and often common-sense and a willingness to listen to the experience of others, especially the mothers, can produce the solution to problems. Slowly, the amount of literature on the subject is increasing and it is advisable to read as much as possible to give a good background knowledge. ASBAH is always available to offer help wherever it can and they have officers dealing with various aspects who are willing to advise. The more that people use ASBAH, the more the association can offer because they, like everyone else, are learning and it is worth considering that they need to hear the good news as well as the bad.

Finally, some may find that what has been written here is rather pessimistic and others may find sections too optimistic. "It's all very well etc., etc.", is a phrase which rings in the ear. However, a realistic attitude must be encouraged and then tempered by a positive approach. One cannot be positive without a certain amount of optimism and I am sure this is much more likely to produce results and encourage new methods of learning and new pathways to a fulfilling life.

REFERENCES AND READING LIST

ASBAH Publications

Children with Spina Bifida at School, Ed. P Henderson,
CB, MD, DPH

The Handwriting of Spina Bifida Children, Joan Cambridge
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Making Our Way - Individual experiences of young people
with spina bifida and hydrocephalus, Ed. Sue Gearing

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Ed. Sue Gearing

Spina Bifida and You - a guide for young people, Colette
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ASBAH Research Reports

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The Further Education and Vocational Training of Young
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ASBAH also has a series of free information leaflets and
a bi-monthly magazine LINK

All ASBAH publications are available from:

ASBAH, 22 Upper Woburn Place, London, WC1 OEP
Tel: 01 388 1382

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All RADAR publications are available from:

RADAR, 25 Mortimer Street, London, W1N 8AB
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ASBAH, 22 Upper Woburn Place, London WC1H 0EP

Telephone: 01-388 1